

SEXUALITY, LEARNING DISABILITY & THE LAW: THINKING TOGETHER
Capacity, Intimacy, Consent & Harmful Behaviour

MONDAY 17th JUNE 2019, 9.30 am – 4.30 pm

Doughty Street Chambers, 53-54 Doughty Street, LONDON WC1N 2LS

Noelle Blackman, CEO of Respond, opened the day by sharing that winning the Howard League Community Award for Restorative Approaches in 2018 acted as an impetus to share Respond's work and bring together people with a shared focus. Noelle discussed the aims of the day; enabling people with learning disabilities and/or autism to have the right to make mistakes, learn from each other and have meaningful relationships. Noelle



explained that Respond was established as people with learning disabilities are often the victims of sexual abuse but it became recognised that they could also be perpetrators. As such they and their families needed support as they were all too often marginalised.

Professor Shelia the Baroness Hollins, Patron of Respond, shared that as a mother of a man with learning disabilities and autism she had great hopes for the multi-disciplinary thinking that could arise from the symposium. Shelia told the story of 'Lucy' who fell in love with 'Peter' at the day centre but whose staff prohibited the relationship resulting in a 15 month wait for permission to date. This prompted a capacity assessment which Lucy failed for not knowing the names of specific body parts and STIs. However after talking to her daughter Lucy's mum was adamant she understood. Ultimately Lucy was interviewed by police as part of a safeguarding query and Peter was accused of a sexual offence despite them wanting to be together. This was said to highlight the not uncommon overzealous reporting of intimate behaviour by care providers, begging the question of whether there is a risk averse culture in social services.

Aswini Weeratne QC, a barrister at Doughty Street Chambers, then gave a talk on the law and capacity to enter sexual relations. She addressed two broad principles of social policy; the need to safeguard individuals and the right to self-determination. Aswini discussed how the law on capacity to enter into sexual relations struggles to achieve a workable and clear balance between the protection of vulnerable adults from sexual exploitation and criminal acts, and the promotion of their autonomy and private lives on an equal basis with other adults. Aswini gave an introduction to the Mental Capacity Act 2005 which provides a protective framework which is expressly based on a presumption of capacity, the ability to make unwise decisions, and the exclusion of intimate life decisions such as marriage and sexual relations from the best interests jurisdiction (s.27).

Stating that otherwise the MCA promulgates a universal test for capacity. Aswini pointed out that the civil and criminal law are at one on this point. She went on to consider the current legal test for capacity to consent to sexual relations in the civil context and the tensions underlying it. Aswini explained the leading case of *Re M (an adult)(Capacity: consent to sexual relations)* [2-15] Fam 61 which endorses the 'act specific test' as opposed to the 'person specific test' under the Sexual Offences Act 2003. Aswini quoted Lady Hale in *R v C* [2009] 1 WLR 1786; "*It is difficult to think of an activity which is more person and situation-specific than sexual relations*". Aswini went on to look at the recent case of *Re NB* [2019] EWCOP 17, which concerns the court's role in a woman's decision to have sexual relations with her husband, *Re A (Capacity: Social Media and Internet)* [2019] EWCOP 2, which is a decision on other areas of modern sexual life that must be traversed with vulnerable adults and the linked case of *Re B (Capacity: Social Media and Internet)* [2019] EWCA civ 913, a decision handed down on 11 June 2019.

Suzanne Wilson and Luthfa Khan of Respond's My Life, My Marriage project then gave a presentation on their work. Suzanne acknowledged that this is a complex area of law which is difficult for professionals to follow. She explained that forced marriage is marriage without the consent of both people where duress is a factor but that where one party is lacking capacity duress is not required. Suzanne highlighted the importance of people with learning difficulties being supported to marry and not pressured to do so. Suzanne presented statistics regarding the prevalence of calls to the Forced Marriage Unit from callers reporting a learning disability and compared these to statistics reflecting forced marriage in the general population. Of note was that learning disabled callers were more likely to be male and more likely to be older. Suzanne went on to explain Mental Capacity Assessments, that they are done by trained professionals and only where there is a 'reasonable belief' that the person lacks capacity. Suzanne stressed the need for an individualised approach with clear guidance.

Luthfa Kahn then went on to explain how the project sought to raise awareness of forced marriage affecting people with learning disabilities from the grassroots level and not just from the legislative arena. She explained Respond's passion for creating resources that cater for their clients and support both families and key community members, helping them understand capacity and what the assessments are trying to achieve. Luthfa characterised Respond as a service trying to make positive change and as the only specialist service in the UK providing support for people with learning disabilities and/or autism at risk of forced marriage. She explained the project's activities including their bespoke psychoeducational programmes. Luthfa then explored reasons why families think about marriage when capacity is lacking, including wanting to support the person's wishes, community and cultural expectations, for safety and security, future care and religious reasons.

The day then progressed to a panel discussion chaired by **Professor Shelia the Baroness Hollins** involving, **Catherine Farrell of MacIntyre, Dr Claire Bates of the Supported Loving Campaign, Christian Buchan of 2BU Wakefield and Liz Wilson, a Respond Family member.**

Shelia posed the first question; How important are relationships, sexual or not to people with learning difficulties and what impact does the attitude of staff have. Claire kicked off by explaining that a national study for adults with learning disabilities found that loving relationships are just as important to them as for everyone else. She discussed how we think it is strange for friends not to have partners but we accept it for people with learning difficulties. Claire said that people think of sex before the relationship itself, staff are worried they will get in trouble and feel the need to conduct a capacity assessment before the couple have even had a date. Claire explained that the study looked at people with learning difficulties and/or autism along with their families and staff,

finding that support workers and family have a massive influence over relationships and that people with learning difficulties often need considerable support to sustain loving relationships. She concluded by stating relationships are absolutely key.

Shelia directed the next question to Liz

Wilson, asking how difficult it is for families to talk to children with learning difficulties about sex and sexuality. Liz explained that it is hugely difficult and that families struggle with a bad reputation for being barriers. Liz spoke of how when learning difficulties are diagnosed the family is given a list of things the child will miss out on and that sex and marriage are high up on that list. Liz pointed out that it is about as difficult for any other parent as it is a difficult topic in any household. Liz noted the added difficulty in that a lot of us learn about sex and relationships by being in the world whereas for people with learning disabilities you need to make the implicit explicit. She rightly noted that most parents would struggle to talk explicitly about sex with their children.

Shelia asked Catherine Farrell what support staff need in this context. Catherine explained that it needs to be made clear to staff that this topic is part of their role and good guidance and training on the issue is required. She stressed that the guidance needs to be accessible as people may not have the confidence so the topic of sex and relationships needs to be normalised in the culture of the service right up to the CEO. Catherine commented that an us and them culture needs to be avoided and staff need to be influenced by the people they are supporting.

Christian Buchan said he was pleased to be listening to in-depth conversations about sex, capacity and consent questioning that given that they are still taboo subjects what hope is there for adults with learning disabilities who are LGBT. Christian stated that at least 2% of adults in Britain have learning difficulties but there is no data showing how many of them are LGBT and this needs to be gathered.

Shelia commented that if two people start getting close there is an assumption that sex is the issue. Dr Claire Bates shared that one of the reasons she chose partner selection for her phd was the rarity of meeting couples who have developed relationships as staff aren't sure if they can encourage the relationship and do not know how to progress the relationship if so. She commented that there is a greater expectation that younger people would have a partner.

Liz pointed out that none of us spend 24 hours a day having sex with our partners and there is so much other intimacy and shared experience they miss out on, sex is a perceived barrier to a bigger relationship.

Catherine Farrell explained that when individuals access new services relationships are not seen as a priority. This prompted Shelia to ask whether people often meet in their supported living setting. Liz shared that in the experience of her daughter she was moved away from her partner and there were difficulties, including regarding data protection in sustaining communication. She explained that her daughter can't give out her phone number and neither can the people she wants the numbers of. Liz shared that she has business cards with her daughter's number on to enable her to stay in touch with people she connects with. Christian Buchan shared that two members of 2BU Wakefield formed a relationship; he commented that watching their confidence



Professor Shelia the Baroness Hollins, Christian Buchan, Catherine Farrell, Liz Wilson, Dr Claire Bates.

grow as the relationship developed was profound. He explained that they were not confident but are now very socially active.

Shelia turned the discussion to the lack of role models for people with learning disabilities wanting to embark on relationships. Dr Claire Bates spoke of how people have low expectations for people with learning difficulties. Individuals see family members having relationships but moving in together in a supported living service comes with barriers and red tape. She relayed stories of partners being refused requests to stay due to fire regulations or the lack of a double bed, pointing out that such issues never stopped her or others for example at University but how people with learning difficulties don't know that they can challenge such refusals.

Shelia commented that when people begin to get close they may want to explore a close friendship and staff may too readily ask questions about sex and put premature ideas in their heads. Liz Wilson shared how no one asked her before she had sex and noted that the joy of a first relationship is exploring it together and how it should be no different for people with learning disabilities, as long as they've had adequate education. Liz spoke of how sex education should occur before there is a real need, this way would be more natural and there can always be reminders later.

Dr Claire Bates explained how some staff are particularly uncomfortable with the subject and need to be willing to find someone to have the conversation and not simply ignore it. Christian explained that 2BU's staff team discuss these issues every day but how the understanding of LGBT issues can be lacking even in the wider population. He noted how when there is work to be done in the mainstream it makes it harder for those with learning difficulties. He illustrated this comment by sharing that as an openly gay man he was asked by a healthcare professional whether it was him or his partner that wanted to be a woman.

Dr Roger Banks, the national senior psychiatric lead for NHS England's Transforming Care, Learning Disability Programme, explained that even if we get over the taboo about sex we are directing people to middle of the road sexuality and forgetting about, sex for fun, sex as risk taking behaviour, we are forgetting fetishes and roleplay and ignoring a whole gambit of human sexuality. Dr Claire Bates agreed absolutely and explained that at Supported Loving they are talking more about for example how to find a sex worker and how to support those with fetishes. She noted however that if we can't even cope with two people with learning difficulties in a monogamous relationship we will struggle to support people with more diverse sexual preferences.

An audience member asked whether there is a similar drive in specialist schools as there is in mainstream schools for teaching on sex and sexuality. Professor Shelia the Baroness Hollins explained how she helped write the sex education curriculum at her son's school. She explained that it has gone through Parliament that from September next year sex and relationships will be taught at school. She explained how parents can withdraw consent but only until the child reaches 15 years old at which point it becomes compulsory. She noted that specialist schools are not exempt from this. Another audience member explained that as a head teacher of a complex needs school she oversaw a sex education programme for 15 years and can vouch for there being some fantastic practice out there.

An audience member who delivers sex education to adults with learning disabilities noted that whilst there is a lot of talk about the right to a sexual relationship this needs to be accompanied by the right to sexual education as a lot of people do not have knowledge of the basic concepts. She

explained that practitioners need to be cautious not to assume sexual education so learning disabled people can make an informed decision on whether to engage in a sexual relationship.

Another audience member noted that we had spoken a lot about individuals with significant professional networks and he was interested if those with fewer professionals, perhaps those with milder learning difficulties were abandoned to their own devices. Shelia stated that by neglecting such people they become at risk of harmful behaviour and of becoming victims in abusive relationships. Dr Claire Bates spoke of research where people with mild learning disabilities or higher functioning autism who had no support from anyone were found to be getting into very difficult situations for example with social media. She spoke of how they can display stalking behaviour because of misunderstanding and how there are a lot of people without formalised support who are particularly vulnerable.

A member of the audience stated that workers are being seen as providing bad support, asking what organisations could do to ensure relationships are considered a key part of life rather than an extra. Catherine Farrell explained that MacIntyre are looking at strategies to ensure support workers are clear about relationships as a priority and a part of their role. Dr Claire Bates proposed that there should be a mandatory training course taken seriously by regulators and organisations.

Shelia concluded the session by stating the importance of working for people with learning disabilities to live ordinary lives like everyone else.

Dr Laura Janes, the legal director of the Howard League for Penal Reform gave a talk about young people in the criminal justice system with harmful sexual behaviour. Laura noted that outcomes for young people who receive a criminal justice response to their offending are much worse off than for those dealt with from a protection perspective. Laura discussed the proportion of young people with sexually harmful behaviours who have learning disabilities. Laura shared that of all her clients she could only think of one client in custody for harmful sexual behaviour who does not have learning disabilities and/or autism or a history of serious trauma. Laura stressed that if children and young people are to feel the full force of the law it is important to understand the context of the offending; specifically the question of whether our young people are growing up in a hyper-sexualised society. Laura went on to discuss the challenges facing children and young people with harmful sexual behaviour in prison, the topic of her doctorate. Laura considered statistics regarding entry into the criminal justice system of children for sexual offences before sharing a case study of a young person with Asperger's who pleaded guilty to three counts of rape of a child under 13. Once his diagnosis was recognised his sentence was reduced resulting in his requirement to notify as a sex offender being time limited rather than indefinite. Laura explored the lack of effective treatment for sexually harmful behaviour in custody, for example how the no work on remand policy results in a delay to treatment and how there are no relevant accredited courses for children in custody, posing the question of whether custody is counter-therapeutic. She spoke about the risk of sexual abuse children and young people are exposed to in a custodial setting as well as the challenges young people face upon leaving custody such as navigating licence and



notification requirements. Laura concluded by proffering some ways forward such as offering a legal education on sexual offending and creative use of temporary release and the circles model.

Helen Gerolaki, the Service Manager at Respond discussed their therapeutic work. Helen talked of how young people with learning disabilities and autism often struggle to understand the complexities of teenage interactions, especially on social media. Helen explained that for a teenager with autism it can be even more difficult than for the neurotypical population. She discussed how at Respond they see a lack of sufficient and meaningful sex education that is appropriately adapted to meet the needs of disabled young people leading to young males being pathologised by the system. Helen pointed out that by society not acknowledging disabled people's need to have meaningful relationships and sexual contact, by denying their right to become sexually active and by not supporting them to learn and understand consent in relationships we are creating an epidemic. She spoke of young men with learning disabilities and autism who go on to unintentionally or even intentionally harm someone while trying to meet their needs and satisfy their urges. She questioned how they could learn about sex and relationships when every time they do something remotely sexual they are risk assessed and given 1:1 supervision that does not have an educational element but is merely to police them. Helen also questioned how they would learn that feeling sexually aroused is not a crime, is not disgusting but a normal experience we all have. She posed further questions such as how we can start the conversations about sex with the parents and care givers and schools. She stated that we need to acknowledge that we are not talking about sex and disability because we find it difficult not because people with learning disabilities and autism shouldn't or can't be sexually active. Helen concluded by observing that society seems to still operate on the basis that people with disabilities don't have sexual desires and needs and are unable to have sex, or maybe they just shouldn't!

An audience member hypothesised that the increase in the number of children with autism being educated in special schools means the change of 'getting it wrong' is increased. Helen explained she did not know if statistically more children were taught at specialist schools but that when issues arise teachers find it hard to deal with it and feel deskilled to give meaningful sex education specific to the child's needs – even in the best willing schools.



Oliver Lewis, a barrister at Doughty Street Chambers introduced three short films regarding Respond's Circles of Support and Accountability (CoSA) model. Following the screening, **Julia Dick, Respond's Service Manager for the CoSA project** explained that the CoSA model is a community based alternative to therapy for those with learning disabilities and/or autism with a history of harmful sexual behaviour or sexual offending. She described the process as the community facilitating re-entry for someone who has done their time, whilst keeping everyone safe. She explained that the Circles model was brought to the UK by Quakers and how Respond developed their own specific model based on the therapeutic and relational principles of Respond and the fact their client group has a history of trauma and abuse.

There was then a panel discussion regarding perspectives on the CoSA model chaired by Oliver Lewis and featuring, Julia Dick, **Dr Susan Hilliard, a CoSA Evaluator; John Woods, a Forensic Psychotherapist; Lorenzo Picco, the CoSA coordinator; Margaret Rust, a relation of a core member and Alison Khan a CoSA volunteer and Respond Trustee.**

Oliver kicked off by asking how clients are referred. Julia explained that core members, who include young people and adults, access the service from a range of sources including schools, learning disability and forensic mental health services as well as referrals from parents. Julia explained that the model is preventative as well as restorative, and that they have found that core members who have offended almost all have a history of harmful sexual behaviour in earlier life that was not addressed which emphasises the importance of a preventative as well as rehabilitative and restorative approach.

Oliver prompted Julia to explain that the five volunteers form a mini community, representing a diverse range of characteristics such as gender, sexual orientation and race. She explained that core members often lead very lonely lives punctuated with engagements with professionals and the idea is that the circle allows the core members to experience agency and belonging. She explained that the diversity of perspectives and experience the universality of life's ups and downs. Julia spoke of how core members are able to ask different volunteers for different things – it allows them to have access to people they otherwise wouldn't from all walks of life who provide positive reinforcement.

Oliver asked what makes a good volunteer and Lorenzo commented that it is mainly that they choose to be there. He expanded on this saying that people with learning difficulties have a lot of professionals in their lives and can feel quite worthless as a result of the support they require. Volunteers however offer a different perspective, a strong message, they are here because they care about the individual because they want to not because they are paid to. Lorenzo elaborated that it is a sought after characteristic of a volunteer that they want to be there to support the individual even if it takes them out of their comfort zone and not because for instance it looks good on their CV. Lorenzo explained that a potential volunteer can have little experience but they have to be committed to supporting the core member for 18 months. Oliver asked what is in it for the volunteers; Lorenzo explained that lots of professionals complain that in their professional capacity they have to follow procedures whereas in circles they are able to build a relationship with the core member in a different way.

Oliver sought the perspective of Alison Khan who agreed that volunteering is a huge commitment. She spoke of when she met with the young person with moderate learning disabilities and talked about the offence the individual refused to maintain eye contact and talked only about his moped to avoid being asked awkward questions. She explained how his confidence grew and within 6 months they were making meaningful progress regarding his emotions. When asked what they set out to achieve Alison recalled that their core member's probation officer had wanted the volunteers to wave a magic wand and sort him out. However the volunteers wanted to help him move on. She characterised the circle as an incredibly positive shared experience and one which gave the core member more self-esteem and self-recognition. She explained how the core member had a chaotic home-life and that he and his mother experienced huge isolation which the volunteers tried to relieve. She spoke of how they pushed the core member's probation officer to organise a mentor into work scheme as they recognised that the circle can't plug all the gaps.

Oliver went on to ask Margaret Rust what the circle meant to her. Margaret immediately noted that they never felt judged, whereas in other situations she felt that people thought if she had done

things differently he wouldn't be how he was. Margaret spoke of how it felt good to be believed. She had always wanted support for her son before the police became involved and the circle provided that support. Margaret told of how her son found the circle comforting and supporting in that he had people to rely on. She said the volunteers made a real effort with him and he was happy to go every week for the 18 months. She commented that this is longer than offered by normal counselling but that this is necessary because his memory is lacking.

Oliver queried how circles are selected and Lorenzo explained that volunteers and core members are put together based on diversity and personality. He gave the example of a core member maybe needing a creative volunteer who would be able to come up with innovative ways to discuss topics. He explained that sometimes core members need male figures as many come from single parent families without a male role-model and by selecting one they have seen special bonds form.

Dr Susan Hilliard explained how Respond manage accountability differently to criminal justice circles in that they address it in an educational rather than confrontational manner. Julia expanded on this point of accountability by recalling how the model originating in a religious community to rehabilitate sex offenders whilst keeping the community safe meant that the core member is answerable to the circle volunteers during the 18 month period. Julia stressed that the circles are rehabilitative rather than punitive. Oliver queried what would happen if a core member disclosed they wanted to engage in an activity such as watching child pornography. Alison Khan said the important thing would be not to overreact and to talk it through by stripping it back to why. She explained the importance of always looking forward. This prompted the question of confidentiality. Alison explained that confidentiality would be broken if someone was at risk of harm but that the core member understands this from the beginning.

John Woods explained that circles are a social form of therapy so are more accessible than psychotherapy and forensic therapy but that psychotherapy can run alongside a circle. John spoke of how this social form of therapy is more visible with the client feeling more connected to the community.

Julia explained that CoSA project places importance on family support and long term work with the core member. She explained that over the last 6 months of the circle they strive to make sure something is there to replace the circle, enabling the core member to build a life in terms of for instance social relations, work and education. They try to establish a structure for life that will tackle the isolation and show the core member they have a place in society which results in sexually harmful and offending behaviour becoming less likely.

Julia discussed how a circle costs approximately £12,000 to run and Susan stated that statistics show the circle model is more cost effective than prison. Susan spoke of how they want the CoSA project to become somewhere individuals can be referred to when their behaviour becomes problematic rather than the issues being ignored or referred to the police – she stressed the importance of professionals feeling safe managing risks.

Margaret spoke of how when her son first went to Respond he didn't talk a lot, wouldn't listen and was controlling of situations but at the circle he made what he considered friends and learnt to listen to people. Margaret said her son was disappointed when the circle ended but he had grown up a lot in the 18 months and made the most of Respond's after care. Margaret explained that he had learnt to communicate and that he wouldn't be let down, the volunteers would always come back and continue to support him. Margaret admitted she was initially apprehensive about the

process but that it turned out to be the best thing. She said the volunteers never made her son feel guilty or that he was in the wrong and that ultimately she was surprised but overjoyed that it worked.

Gina Miller, a long-time supporter of Respond gave a moving keynote speech in which she shared her personal experiences. Gina spoke of how she had been a supporter of Respond since 2015 as her foundation works with small community charities who find it difficult to obtain funding. Gina shared that when she found out about the topic of the Symposium she cried as she has a 32 year old daughter with special needs. She then caveated that she does not like the term 'special needs' and so throughout her daughter's life has told her she had different needs. Gina said that when her daughter turned 16 she realised she was a sexual being and had the right to be as sexual as any of us do as loving is what makes us human. Gina spoke of asking her daughter's college if they provided sex education and being met with a horrified response from the college who reported Gina to social services for asking an inappropriate question for a parent of someone with different abilities. Gina subsequently appeared before the social services panel and quoted the UN convention to demonstrate that her daughter had every right to have access to life like everyone else. They did not know what to say.



Gina explained that she tried to talk to her daughter about sexuality as with her other children and that they did what they could as a family to make her aware of her body and sexuality. However, Gina shared that as much as they prepared they could not protect her and that over her life her daughter had had horrendous experiences, the takeaway being that parents can only do so much, they need help. Gina told the audience that at her daughter's life skills course they had helped her set up a Facebook page, despite Gina having kept her away from social media. One Friday when her daughter was staying at her best friend's house Gina had a feeling something was wrong. Gina called the best friend's mum and found out her daughter was not there. Upon calling her daughter she discovered she was on the Elephant and Castle roundabout. Her daughter had met a boy on Facebook who had invited her to a party only he turned out not to be a boy but an older man who was making her go back to his flat. It turned out he had been grooming her for 6 months. Gina told her daughter to find a black cab with the light on and her daughter was saved. However Facebook refused to let the family close down Gina's daughter's account, they said that as she was over 18 they had no responsibility. Gina explained that she had to go to the President of Facebook to insist it was taken down.

After her daughter left college Gina found an extraordinary residential college which operated as a fully working hotel which would train her daughter to work in the industry. Her daughter was accepted to train but the college said she needed to be sterilised or have the implant as they did not have the staff time or training to deal with young people's sexual behaviour. Gina refused this but they took her to get the implant anyway.

Gina described how when her daughter was 25 she met a boy. The boy's family seemed nice and after about a month they invited Gina's daughter on holiday. Gina appreciated the need for friendship which is sometimes hindered by protection so agreed. However, the night before the

holiday whilst packing her daughter's bag Gina asked where she would be sleeping. Her daughter replied she would be in the boy's bed, she said his mum had told him they could have a baby and he could go live with Gina's family.

Gina explained how those with learning disabilities get abused for game and satisfaction. She cautioned that when we repress their need for a relationship we make them more vulnerable. She emphasised that every one of us has the right to love and be parents.

Dr Roger Banks concluded the day by noting that there is a long established tradition when talking about learning difficulties to tell stories, as it is the human narrative that hits where it hurts. He also invited the audience to write on post-it notes what they would do differently following the symposium.

